Diastat Bill Testimony

Jim Ross, Father of Emmett (7 year old with Eplepsy)

Wed, Feb 21, 2013

My name is Jim Ross and I am the father of Emmett, my 7 year old son who has Epilepsy. I would like to speak in favor of this legislation which, at its heart, protects the welfare of some of CT's most vulnerable, our children with Epilepsy. Epilepsy can strike at any time and any place and so much like a life-threatening allergic reaction, a seizure can kill if untreated quickly. And like life-threatening allergic reactions which permit the use of the Epi-Pen by trained paraprofessionals, coaches and teachers, this Diastat Bill similarly empowers these school professionals who volunteer to be able to administer a prescribed and pre-measured dose of Diastat IN CASE the school nurse is not immediately available. In what civilized society, should we stand by and watch as a child's life is slowly strangled by the terrifying grasp of a seizure? And especially when we have the antidote and trained and willing volunteers to administer it? What special interest or situational unpleasantness should prevent us from putting the vulnerable life of a child first?

This piece of legislation has been specifically drafted to AFFIRM the school nurse's primary authority to oversee and manage the emergency medication administration plan and to be the "first stop" in any seizure emergency. Only if the school nurse is not immediately available, does the trained paraprofessional, teacher or coach spring into action with the prescribed dose of life-saving medication. There is absolutely no danger from the medication or its administration to the child. Nearly every adult in my family has had to administer Diastat at one point and none of us has a medical degree but EVERY time we gave the medication (without harm), it broke the seizure....every time.

As life-threatening as Epilepsy is, it is also not uncommon. In a recent 2010-2011 CT State Department of Education study of Health Services in CT public and private schools Diastat was used in 18% or about 25 school districts to break a seizure during the 2010/2011 school year. After use of the Epi-Pen for allergic reactions, Diastat is the next most often used emergency medication in our schools. There are over 2,700 students in CT who have been diagnosed with seizure disorders. This is more than the 2,400+ children diagnosed with Bee Sting allergies for which the Epi-Pen can be administered by a trained non-medical school personnel. As a parent, It is concerning to note that 1 in 5 secondary schools may have only one nurse for over 750 children. Even the best nurse can not cover all the students, attend every game, be on every bus and cover every field trip. Like the school nurse, 911 paramedics are only effective if they are immediately available. This Diastat Bill like the one recently passed in California effectively closes the emergency care "gap" for our children with Epilepsy.

So please extend to our children with Epilepsy the same protection that you provided children with life-threatening allergies....enable non-medical school personnel to administer life-saving medication when a school nurse is not immediately available.

Thank you for your time and consideration...below is some select data and findings from the CT State Department of Education's 2011 "Health Services Program Information Survey Report". The link is CT Health Services Program Information Survey Report 2011

Connecticut State Department of Education Health Services Program Information Survey Report October 1, 2011

- -169 surveys were distributed with 148 responses yielding an 88% return -
- -93% were public school districts
- -data collected during 2010-2011 school year

Table 6: Number of students with specific Seizure Disorder Health Needs

Public School Students-

2524

Private Non-Profit School Students -

213

Total Number of Students – 2,737

Table 8: Emergency Medication Administration Percent Response

Medication

Percent of Districts having used this medication in the past year

Glucagon

2.4%

Diastat

18.0%

Epinephrine

37.3%

-18% of the 148 respondents used diastat in the past year. The Study states: "Districts regularly prescribe emergency medications as needed including glucagon, diastat and epinephrine."

Table 14: 911 Calls in Public and Private, Non-Profit Schools

Sixty percent of respondents identified injuries as the most common reason for 911 calls. "Other" was reported as the second most common reason for 911 calls followed by "anaphylaxis" and "seizure."

Table 3: Nurse-to-Student Ratio Percent Respondents

	One Nurse to	One Nurse to	One Nurse to
	250-500 Students	501-750 students	More than 750 students
Elementary nurse-to-student ratio in district	t 73.0%	24.6%	2.5%
Secondary nurse-to-student ratio in district	32.2	47.9	19.8

The Study states: "A majority of Connecticut schools meet national guidelines that recommend a school district have a nurse-to-student ratio of no less than 1 nurse to 750 students. However, survey results suggest that 1 in 5 secondary level schools in Connecticut may not meet this guideline."